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ABSTRACT

The pamphlet discusses several puzzling disorders of childhood, including autism, atypical personality development (childhood psychosis), psychosocial dwarfism, and Tourette's syndrome. Psychosocial dwarfism is said to be characterized by a marked reduction in physical development and by immaturity in behavior, while Tourette's syndrome involves chronic, multiple tics that spread and come to include larger involuntary body movements. The detection of developmental disabilities in children is briefly reviewed, along with general suggestions for their intervention. (DLS)

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Science Reports

National Institute of Mental Health

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NEW LIGHT ON AUTISM AND OTHER PUZZLING DISORDERS OF CHILDHOOD

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Foreword

Mental and emotional disorders affecting children today represent one of the most intensively studied dimensions of childhood health and illness. The need for such emphasis is clear: Upward of 12 million children and youth in the United States experience some measure of mental health problems, and, of these, approximately 2 million youngsters suffer severe mental disability and related handicaps.

For more than a decade, child mental health activities—including research, the development of specialized services, and the training of child mental health professionals—have been the foremost priority of the National Institute of Mental Health. This report describes one significant aspect of our effort.

Dr. Donald J. Cohen is psychiatric director of the Children's Clinical Research Center at the Yale University School of Medicine. Through his program, Dr. Cohen is able to draw on the expertise of diverse and dedicated child development specialists. Collectively, the team has developed improved understanding of such puzzling and tragic disorders as childhood autism, childhood aphasia, and other types of severe disturbance afflicting infants, children, and adolescents.

Among the most productive contemporary areas of research are those involving studies of brain activity and the effects of biochemical imbalances in the central nervous system on a child's subsequent development.

Yet, while biologically oriented research has done much to relieve the burden of guilt that, in the past, has been mistakenly assumed by parents of many mentally ill children, Dr. Cohen gives strong voice to the continuing needs for effective parenting capabilities and supportive, loving family environments as vehicles for reducing the tolls taken by the various disorders.

In addition to their research on the causes and treatment of primary and secondary autism, the Yale researchers have

studied other developmental disabilities such as psychosocial dwarfism—a condition characterized by reduced physical development and immature behavior—and Tourette's Syndrome, a disorder that is manifest in disabling and often psychologically devastating chronic, multiple tics.

A major advantage of the broad focus on childhood disorders lies in the scientists' ability to differentiate more precisely among types of illness that may share features but require distinct treatment approaches ranging from medication to behavior modification.

Answers to the crippling disorders of childhood are not all in. Yet much is known, and we intend that this report and other descriptions of ongoing research will encourage parents to seek help that is available and to take heart from the effort that is being made on their behalf and that of their children.

Herbert Pardes, M.D.
Director
National Institute of Mental Health

New Light on Autism and Other Puzzling Disorders of Childhood

by Herbert Yahraes

Micky at birth weighed almost 8 pounds and appeared to be perfectly healthy, yet he showed no pleasure when held by his parents and did not respond to their smiles or other shows of affection. His motor development was normal, and he walked when he was 16 months old. But he never babbled. When he was 18 months old, he said something that sounded like "no"; it was his first and last word. By the time he was 2½ years old, he was completely uninterested in social relations and totally unconcerned by separation from his parents. During the next few years he remained easily distracted and very hyperactive. He was either extremely anxious or extremely lethargic. He also swung between periods of aggression directed at himself and periods of aggression directed at others.

At 7½, Micky was attractive and bright eyed, but his only attempts at communication were aggressive lunges toward the medical staff of the hospital where he had been taken for treatment and "whining to his mother to indicate hunger." The doctors could find no specific neurological or biochemical abnormalities. They prescribed one of the phenothiazine drugs commonly used against schizophrenia. For a while he improved, showing decreased activity and increased social relations, "and for the first time he was able to follow simple instructions." After 4 months, though, he lost these gains, and "even with manipulation of the medication, there was no way of reducing his activity and destructiveness." Because life was becoming harder and harder for his family, Micky was admitted to a residential treatment institution.

During the first four months in the school, he made educational and social gains. Then, again, at age 8½ years, he had another radical mood shift, which left him uncontrollable, banging his head all day, and bruising himself. During this time, he seemed uncontrollable, and at times he required restraints to prevent him from hurting himself. He then had another shift, and he would sit for hours, holding a nurse's hand, apparently in great distress and muttering 'un, uh.' He pulled his hair, leaving wide areas of baldness. A detailed neurological and metabolic evaluation was performed, revealing him to be thinner, more distressed, and even more socially unresponsive than he had been one year before, but otherwise with no indications of any central nervous system disturbance.

Micky suffers from *primary childhood autism.* His story is told by child psychiatrist Donald J. Cohen, Associate Professor of Pediatrics, Psychiatry, and Psychology at the Yale University School of Medicine and Child Study Center. Cohen, who is also Psychiatric Director of the Children's Clinical Research Center, Yale University School of Medicine, is one of the country's leading authorities on autism and several other neuropsychiatric disorders of children which are discussed in this article. Although these disorders still have many puzzling aspects, authorities such as Cohen are making progress in distinguishing one from the other, elucidating subgroups, getting at the basic causes, and testing drugs and other forms of treatment.

In addition to Micky's classical or primary autism, there is a condition known as *secondary childhood autism.* Development and behavior in this type may be almost the same as in the other, but the trouble seems to be secondary to recognized disturbances, such as brain damage associated with measles or with lead poisoning, inborn errors of metabolism, and a type of blindness (retrolental fibroplasia) sometimes following the administration of too much oxygen to premature infants at birth.

"The universal symptom of autism," Cohen points out, "is the inability to relate to people and social situations in a normal way." This inability is accompanied by aloofness, inaccessibility, and lack of interest "which superficially may resemble the picture presented by the most severely mentally retarded child. However, the autistic child's usually normal developmental landmarks and relatively normal physical development differentiate this type of disorder from mental subnormality."

One child out of every 3,000 has autism. The condition may be noticeable from the very start. The child's attention may fade in and out. He is likely to be uncomfortable when held. He may cry almost without letup, or he may seem unusually quiet. Around the age of 1, his main occupation may be looking at his fingers or banging his head against the crib—for

hours—or he may become occupied with one toy and reject everything else.

Research concerning autistic and other developmentally disabled children requires an integrated team of experts with special competencies and interests. The core research team at the Yale Child Study Center working with Cohen includes a developmental psychologist and educator, Barbara Caparulo; a research child psychiatrist, Dr. J. Gerald Young; and other research associates. They work in collaboration with other clinical investigators—Dr. Bennett Shaywitz, a pediatric neurologist who heads the section on pediatric neurology at Yale; Dr. Myron Genel, the chief of the section on pediatric endocrinology; and Dr. Julian Ferholt, a child psychiatrist who specializes in psychosomatic disorders of early childhood. In addition, neuroradiologists, pharmacologists, psychologists, and human geneticists join in collaborative research projects which no one could undertake alone.

Biologically oriented clinical research with children is expensive. During research hospitalization, disturbed children require private nursing care and the almost full-time attention of a researcher. Specialized tests and laboratory procedures may cost hundreds of dollars. Thus, a several-day research study of one autistic child may cost over $1,500 in time, laboratory studies, and hospital costs. The research of the Cohen group is funded by several sources, both public and private. The Children's Clinical Research Center is supported by the Division of Research Resources, National Institutes of Health. A special Mental Health Clinical Research Center will be opened as the result of a 1977 award from the National Institute of Mental Health; co-directors will be Cohen and psychiatrist Malcolm Bowers. Private foundations, such as the William T. Grant Foundation and the Ford Foundation, have funded certain aspects of the research. Most gratifying, according to Cohen, has been the support of private donors whose involvement in the research stems from being parents of children who have the disabilities being investigated.

The Saddest Disease

Of all the afflictions of childhood, primary autism may well be the saddest because its core symptom, in Cohen's words, is "the inability to relate to people and social situations in a normal way." Even to the mother, the autistic infant may respond no more warmly than to a piece of string or a flashlight.

Yet some autistic children display amazing word recognition skills. They can read very well, and they can also repeat complex sentences read to them. They cannot explain, however, what they have read or heard. "Autistic children," Capa-

rulo and Cohen report, "are notorious for their abilities to repeat strings of sentences, to remember routes to places months or years after first being exposed to them, to notice changes in the placement of furniture or the presence or absence of toys in an office, and to remember dates and numbers...." What seems to be impaired "is the *significance* or *meaning* of the objects, events, and people, and relations among them, reflected in the written word or aural communication." Examination usually uncovers nothing neurologically wrong.

For many years, as even occasionally today, autism was laid at the parents' feet. Fathers and mothers were judged to be cold, to show little more than a polite interest in their child, to be incapable of extending love. Many parents—in particular, many mothers—grieved for years because of the surmises of child experts.

Cohen puts it this way: "The hope during the 1940's and 1950's that one would find parents to blame was both mean and, yet, optimistic. If autism could be caused by parental feelings and action, we would have a much greater sense of conviction in the power of environmental provision and optimism about what could be potentially undone. Today, however, parents of autistic children are considered to be like the parents of other handicapped children whose care poses inhuman burdens. Parents are usually unhappy, worried, angry, discouraged, and exhausted. But they are not, as a group, unconcerned or unloving." Many of the parents of the autistic children studied by Cohen keep their children home rather than send them to a residential treatment facility. And for these parents, "marital strife, separation, and divorce are almost expected outcomes," because an autistic child places an "impossible stress" on a marriage.

Instead of environment, congenital endowment may somehow be playing a hand. A number of investigators, including Cohen's group, have found a "relatively high incidence of depression, language difficulties, severe psychological disturbances, and anxiety of eccentricity in the blood relatives of autistic children."

Notions about the root of the trouble are beginning to accumulate, and these have nothing to do with relationships within the family. One basic problem appears to be the autistic child's inability to generate rules for dealing with information received through the senses—or even to understand these rules when they are explained. Caparulo and Cohen, for example, have studied a bright, autistic 10-year-old who liked to draw a popular restaurant over and over again. His drawings were accurate; obviously he had a sense of size. Yet, when he was asked to arrange eight geometric shapes according to size, he was baffled. In other words, he could

draw a building according to scale, but he could not understand the concept of smaller and larger.

In some autistic children, another problem seems to be an abnormality or dysfunction in the body's system for regulating the state of arousal and attention. For example, the rate at which the heart works and the blood flows usually changes as states of attention change. But Cohen and an associate found that in the most disturbed children such rates did not follow the normal pattern. Such children apparently were actually rejecting sensory messages that in other children led to higher levels of arousal. Cohen believes that such rejection is not voluntary but is caused by some abnormality in the ability to process external stimuli. Recent work in the laboratories of Cohen and other investigators suggests that the most disturbed of the children may be almost habitually in a state of hypervigilance. Such a state "may be associated with recurrent cognitive confusion and a compensatory withdrawal and turning inward of attention to avoid environmental bombardment."

Far from trying to be contrary or to cause pain and grief, the autistic child, impaired cognitively and attentionally, may be simply trying "to impose order on his world." Many of his symptoms, the Yale investigators point out, "may be seen as compensatory mechanisms." As one 16-year-old movingly explained: "I am sad about my body, but it's no good to be sad. You should try to make jokes when you're feeling sad."

Some aspects of autism, Cohen speculates, may be associated with overactivity of the dopamine system. Dopamine is one of the so-called "biogenic amines" essential for proper brain functioning. It is, in fact, a neurotransmitter. Like other neurotransmitters, each apparently acting in its own portion or portions of the central nervous system, it carries from one nerve cell to another, at an unbelievable speed, the electrical signals propagated in the brain. A transmitter serves in effect as a bridge over the synapses, or the tiny clefts between nerve cells.

Cohen notes that drugs, such as Haloperidol and the phenothiazines, which inhibit dopamine action have therapeutic value in some cases of autism, while drugs, such as the stimulant, dextroamphetamine, which increases that action, exacerbate the symptons. Moreover, in the cerebrospinal fluid of severely autistic children, he has found greater quantities of dopamine breakdown products. This discovery suggests that in these children an excess amount of this brain chemical is being manufactured and broken down. Its release and catabolism have been shown to be greatly affected by stress. It may well be that, as seems to be the case in schizophrenia and depression, in autism a disturbance in the neurotransmission system may help cause the stress, instead of the

other way around. However, as Cohen is the first to point out, a great deal of research by a number of investigators will be needed to establish the truth or falsity of these and related ideas.

Nonetheless, the recent discovery by other scientists of two groups of neurotransmitters quite different from those found earlier seems only to strengthen the transmitters' importance to mental health. The new groups have been named the enkephalins and the endorphins. Chemically, they are peptides, or combinations of amino acids, which in turn are the building blocks of protein. Cohen and J. Gerald Young point out that the newly found compounds affect the processing of sensory and emotional signals and "may be involved in modulating pain and pleasure." They have wide implications for understanding and treating a variety of mental illnesses. Among the subjects to be investigated, or re-investigated, as the result of the new findings, these researchers list "the turning away from sensory stimulation and the unusual sensitivities of some autistic children," the hypervigilance of psychotics, the inability of clinically depressed persons to experience pleasure, and the nature of drug dependency.

Other investigators have found that one of the main hormones, triiodothyronine, produced by the thyroid gland, makes for improvement in some cases of autism. Cohen's group, in turn, finds that some autistic children show marked swings—ranging from the *hypo*thyroid to the *hyper*thyroid level in a few days—in the amount of thyroxine, another principal thyroid hormone. Because of these and the earlier findings, Cohen and other researchers are studying the way in which thyroid hormones affect the metabolism of brain neurotransmitters.

One role of thyroid hormone, Cohen suggests, may be to sensitize neurons to the effect of the various transmitting agents. When the flow of thyroid hormones is reduced for some reason, the brain tries to maintain a steady state by increasing their production and use. On the other hand, when these compounds are produced too rapidly, the brain signals the thyroid to ease up.

The marked swings of a thyroid hormone noted in severely autistic children may go hand in hand, under this hypothesis, with broad swings in behavior. Thus the effectiveness of thyroid medication may be related to its "dampening of fluctuations."

Another factor apparently at work in at least some cases of autism is a higher-than-average amount of lead in the blood, which even in normal children can lead to disordered behavior such as irritability and lessened attention. The Yale investigators found these higher levels—in some cases

well above the toxic mark—among autistic children as a group. Presumably they arise because many such children, besides having peculiar eating habits, swallow or at least take into their mouths a wide variety of inedible material, some of it containing lead. The lesson is that autistic children should be tested for the presence of lead in the bloodstream though they rarely are. Lead does not cause autism, but it can add to the problems.

What happens to autistic children as they grow into adolescence and then adulthood? Most of them remain in institutions or are placed there. Cohen and his fellow workers report the feelings of a devoted mother, who had spent every day with her son during his first 17 years, when she first brought him to a residential center. "I knew that as soon as I brought him there," she said, "he would be as happy as he was at home. He didn't seem to miss me for a minute." But Cohen estimates that there are a "fortunate 10 to 15 percent of older autistic individuals with language abilities and improved social relations who may seem merely "odd, eccentric, or very immature." In social situations, their behavior "usually lacks spontaneity and reflects the hard work they and their parents and teachers have put into education. They must be taught social conventions, for example, how to say 'fine, thank you,' instead of honestly responding with a discussion of their daily lives when they are asked how they are doing."

> In school, such autistic individuals may show areas of high intellectual ability and may learn to read well, yet their comprehension may be relatively limited, and the information they acquire may be of very questionable value. The older autistic individual's speech usually remains deliberate and stiff.... In spite of major improvements, these older individuals remain anxious and perhaps depressed as they recognize their limitations; they may have odd mannerisms or flapping behavior, especially when they are upset or excited, and they may be unable to engage in imaginative activities or work or play in a mutually meaningful way with others.
>
> For the less fortunate autistic child whose language does not progress, behavior during the school age and adolescent years remains clearly continuous with that of the preschool years. His overactive behavior may decrease with training but his ability to communicate. . . or relate with peers or adults may be extremely limited.

Childhood Aphasia

Perhaps the most common symptom of pre-school children referred to child-development clinics, Cohen reports, and certainly the most common symptom that brings autistic children to child-development specialists, is slowness in begin-

ning to talk. Among such children is a subgroup diagnosed as having primary childhood aphasia, "usually defined as the failure to develop, or difficulty in using, language and speech in the absence of mental retardation, deafness, or a primary emotional disorder." (Other terms used for the same condition are *congenital aphasia* and *idiopathic acquired aphasia,* both meaning essentially that the cause is unknown.) It differs from adult aphasia because the latter is a *loss* of language—following brain damage caused by a stroke, tumor, accident, or illness. In childhood aphasia, though, there is a failure to *acquire* language.

Among 30 children with primary childhood aphasia studied by Cohen and Caparulo, many if not most had been diagnosed at some time as autistic. However, "characteristically their gestation and delivery were normal, the first year or two of life was completely uneventful, and the child was thought to be a healthy, socially attentive youngster by his second birthday. Then, sometime between age 3 and 4, the family became increasingly anxious about slow language development. Usually, by the late pre-school years, the child began to show increasing activity, difficulties in deploying attention, and irritability. If seen in a psychiatric facility, the diagnosis of childhood autism might have been made, although parents were quite clear that the child showed warm, social attachment, particularly to his mother, and could make use of mime and gesture in a meaningful way...." Autistic children, in contrast, "do not establish meaningful, affective relations, and they often actively resist making social contact...." However, aphasic children do become "increasingly agitated and disturbed as they recognize their difficulties in communicating." Among children with primary or congenital aphasia, some have an additional difficulty: They cannot distinguish environmental sounds, such as a cat's meow or a dog's bark. Earlier investigators designated their trouble as *congenital auditory imperception.*

There are several other groups of childhood aphasias, sometimes less severe than the congenital condition. One major group is called *developmental* because it occurs slightly later in childhood. Children with that type may achieve the use of sentences, Cohen reports, while children with congenital aphasia generally do not develop the use of even phrases. In general, child asphasics comprehend language much better than they produce it. They are alike, too, in having more social attachments with their parents than autistic children have, and sometimes with many other people as well. And they give evidence of a well-integrated imaginative life.

Some clinicians believe that autism and childhood aphasia are related, but Cohen points to a fundamental biological

difference. The electroencephalograms, or EEG's, of autistic children tend to be "normal or borderline abnormal, often showing some immaturity or lack of symmetry." But the EEG of an aphasic child "most often reveals dramatic, seizure-like patterns of discharge." These "may be most clear overlying the areas of language function, but may also exist in the occipital or in the minor hemisphere. The EEG seizure patterns are not associated with clinical seizures [as in epilepsy]; in fact, they may occur several times a moment without any clinical change."

Interestingly, though, the use of medicines that generally prevent or reduce the number of seizures in an epileptic does sometimes work with aphasic children. Cohen reports: "The reduction of paroxysmal EEG activity by the use of anticonvulsants such as Dilantin has, in our hands, sometimes led to very gratifying improvement in the language and behavior of the aphasic child." This suggests "that the paroxysmal EEG abnormality may represent a cortical disturbance and one intimately involved with the child's organ of language and ability to learn and use language."

This investigator continues:

> Aphasic children may create for themselves a rich repertoire of signs and gestures and may often take to the use of the American Language of the Deaf with great facility and pleasure. Learning to communicate opens up new avenues of social interaction and allows the child, sometimes for the first time, to meaningfully express abstract ideas. Mute autistic children may also be instructed in the use of the American Language of the Deaf, and we have seen how several of them have shown improvement in their general functioning and the ability to learn a reasonably extensive repertoire of signs. However, in contrast with children with aphasia, those with autism remain severely limited in their use of gestures, which they never acquire spontaneously, and their gesture and mime language remain stereotyped and directed by immediate needs, rather than by the wish to make social relationships more accessible.

Still, says Cohen, there are just as good reasons for associating childhood aphasia with primary childhood autism as there are for completely distinguishing between them. "Perhaps the most persuasive evidence of a fundamental relationship...comes from studies of sibships." The Yale group is studying several families, each of which has several children. And in each case, one of the children has symptoms of autism, another of aphasia, a third of a delay in acquiring language. Further, "The family histories of children with autism sometimes reveal relatives with delayed language characteristics, and this is a finding which is quite characteristic of the families of children with childhood aphasia."

Continued study of the likenesses and the differences among many childhood disorders, Cohen is sure, will lead to

enhanced means of treatment. He points out, for instance, that autism, obsessive-compulsive "character disorders," mental retardation, and a condition discussed later, Tourette's syndrome, though all seemingly quite disparate, do have one feature in common—the display of repetitive, stylized behavior. If researchers can find the basis for controlling such behavior in one disorder, they can go on to show how that disorder is biologically linked to or set apart from the other disorders.

As the aphasic child grows older, Cohen reports, "every investigation has found increasing hyperactivity and lack of ability to attend." Other universal behaviors include "aggressiveness, distractibility, memory defect, immaturity and silliness, seclusiveness, social withdrawal, reduced ability to deal with abstract thinking, and variability of performance on IQ tests."

This investigator notes that "the sense of immaturity and silliness observed in most aphasic children is heightened by an intensely clinging and symbiotic mother-child relationship, in which the child sees his mother, who is often the only person who understands him, as representing the only stable and reliable source of emotional and social support."

Cohen points also to the misery caused by disagreement among physicians. "Disturbances in the parent-child, usually mother-child, relationships also stem from the difficulties encountered in the course of seeking a diagnosis and treatment. As parents persevere in trying to find appropriate education and care for their child, they often receive conflicting and confusing opinions. For years they may be the only ones who remain convinced that the child is not hopelessly retarded or autistic. In the process, they may become progressively more protective and defensive."

As one example of the confusion and misery visited upon parents, Cohen cites a 1969 report by another investigator: During a 5-year period, out of 24 children diagnosed as schizophrenic or autistic and referred by child specialists or psychiatric units to special schools, "26 percent were found to be primarily aphasic with secondary autistic reaction."

What happens as the aphasic youngster grows up? Usually, Caparulo and Cohen agree, the language difficulties persist well into adolescence: "Most often the child increases his word dictionary, sometimes at a startling rate similar to the early vocabulary spurt of normal 2-year-olds. Combining these words into syntactically correct sentences remains difficult, however....Words connoting abstract qualities like temporal relations and affective states or emotions remain elusive...."

In addition to the treatment procedures mentioned earlier, behavior-modification techniques have been used successful-

Then, too, children with atypical personality development have much more organic impairment. They have a history of traumatic deliveries; their EEG's are abnormal; their facial appearance is often unusual. Autistic children tend to look much like their parents and siblings, while those with atypical personality development "often look as though they belong to another family." Moreover, their disturbance is less severe than the autistic child's, though later on it may develop into childhood schizophrenia. Finally, Cohen has found, the children with atypical personality, unlike those with autism, tend to come from families that are stressed or disorganized.

A variety of causes or of symptoms suggesting a cause has been found in Cohen's group of such children. Among them are brain damage from lack of oxygen at the time of birth, epileptic-like seizures, and hypothyroidism. However, "often, the biological predisposition seems compounded or even overwhelmed by the strains in the family and the stresses imposed on the child." This finding contrasts with what the investigator has found in childhood autism.

Children with atypical personality development, suffering from anxiety, learning problems, and difficulty in forming social attachments, Cohen notes, can sometimes be very much helped by early psychotherapy. In individual treatment or in treatment in small groups, such as done under the direction of Dr. Sally Provence at the Yale Child Study Center, children with atypical personality development can be helped to modulate their anxiety and to slowly progress in forming trusting relations with adults. In addition, their parents can benefit from guidance that helps them to understand their child's individual sensitivities and needs, as well as to deal more effectively with their own interpersonal and psychological problems.

Strengthening the family life and improving parental competence can have immediate impact on the child's development. Some children with atypical development may benefit from medication; many will require special education or education designed to be more responsive to their individual needs.

Recently, atypical personality development has been conceptually related to one end of the spectrum of childhood difficulties known as "minimal cerebral dysfunction" or "minimal brain damage" (MBD). Children with MBD often suffer from cognitive problems, hyperactivity, impulsiveness, and immature personalities. It has been hypothesized that the most extreme form of this disturbance may be, or appear to be, one type of atypical personality development. For some children with MBD, stimulant medication may help.

Psychosocial Dwarfism

Yale investigators in the Children's Clinical Research Center and Child Study Center are also working to elucidate the causes and treatment of another peculiar and disturbing condition in children known as *psychosocial dwarfism.* It is characterized by a marked reduction in physical development and by immaturity in behavior. It does not respond to growth hormones. And it seems to occur only in families facing an abnormal amount of stress.

When psychosocial dwarfs are hospitalized, Cohen and other researchers have found that they show "a remarkable acceleration in physical growth." Before or at the start of the hospital stay, tests show that their production of the growth hormone has been blunted. With hospitalization, though, this production swings back to normal. "Such children, in hospitals," Cohen says, "often display a voracious appetite, abnormalities of sleeping, and short attention. However, improvement may come within a few weeks, or a few months at most. It brings normalization of sleeping patterns, and appetite, and better social relations."

More and more such cases are being seen at university and other hospitals with large child-care departments because, Cohen suspects, such children used to be diagnosed as having an endocrinological abnormality. "But now," he continues, "we can test much better for pituitary function, and we can say, 'No, they're not like those other children—those with real pituitary disease, the hypopituitary dwarfs. Those are children from a normal environment who fail to grow. They respond to growth hormone; the psychosocial dwarfs...do not.'"

The condition occurs in all social classes but probably in only the most disorganized families. Cohen's colleagues, Drs. Fesholt and Genel, have studied several such children over long periods of time. One child studied by Cohen was brought to the hospital for evaluation when he was 12 or 13 but looked 6 or 7. Various doctors had suspected a chronic gastrointestinal problem or perhaps a chronic pulmonary disease. The boy came from a middle-class family and had developed normally during the first few years. But when his father left to serve in the army for several years, the mother became depressed and the child greatly reduced his eating. Just before it was time for him to start school, the boy was eating hardly anything; by first or second grade, his linear growth had stopped. When brought to the hospital, he was very small, very immature, and depressed. But endocrinologically he was sound. His growth hormones were normal.

How do doctors treat such a child?

Cohen answers: "We give them psychological support, love,

an atmosphere in which they are not constantly experiencing anxiety, and the opportunity to learn how to take pleasure in normal eating.

"For any long-term success, though," Cohen continues, "the parents have to be educated, or re-educated, to parenting." Among other things, this means they must recognize the need for calmness, order, and discipline in the home; the importance of the parental presence; and the need for parental interest in the child—not feigned but genuine interest so that the child really knows he has someone who will listen to and help him do something about his troubles and worries. And children have more worries than most adults either remember or believe. Where there is no capable parent available, an appropriate substitute must be found.

The investigator calls attention to a disorder known as *anorexia nervosa,* or refusal to eat because of psychological overconcern about obesity, which occurs primarily among adolescents and young adults and results in dangerous weight losses. "Why in some ways," he asks, "isn't the appetite disorder in these psychosocial dwarfs similar to what we see in some young people later on?" He and his group have been intrigued by the possibility that psychosocial dwarfism is provoked by the stress and anxiety of the pre-school years, while anorexia nervosa is in some way triggered by the endocrinological changes of adolescence. But he is inclined to think that the two conditions are separate, not related.

At the basis of the trouble in psychosocial dwarfism, Cohen hypothesizes, is a disturbance in the metabolism of the brain chemicals known as biogenic amines. This disturbance affects the functioning of the hypothalamic-pituitary gland system, whose many jobs include the arousal or suppression of appetite.

Why, usually, is only one child in a stressed family afflicted? Cohen answers with another question: Why, usually, is only one child in a family autistic? In the former case, Cohen reports, "most investigators have looked for, and have found, difficulties in parent-child relations." But Cohen wonders if psychosocial dwarfism does not, at least in part, result from an aberration in some of the children themselves. In other words, there may be something in the child—something in the workings of the brain chemicals—that with more than average ease goes out of kilter under family stress. To Cohen, such a hypothesis is consistent with the observation of the disturbances in parent-child relationships produced by autistic children. He hopes "it will not be necessary for a generation of parents of children with psychosocial dwarfism to be made to suffer the same torment at the hands of caregivers as have the parents of autistic children from 1943 until the early 1970s."

Tourette's Syndrome

The Cohen group has also studied and successfully treated a strange and disconcerting condition, less rare than commonly believed, known as Tourette's syndrome or chronic, multiple tic syndrome. It is first manifested by tic-like blinks and grimaces in the early school years. As the investigator points out, transient tics are quite common in kindergarten and first-grade children. But in children with Tourette's syndrome, the behavior spreads. Instead of involving just blinking and grimacing, it comes to include shoulder jerks, body jerks, and then, often, repeated movements such as shoulder shrugging, hand jerking, or kicking. The person also makes little noises, "which may sound like whispering or the whistle of little mice"; later he may say words aloud; finally, without apparent reason and with no means of control, he may loose a torrent of vulgar and obscene language, to the dismay of those around him and to his own distress—particularly, as is often the case, if he is a sensitive, intelligent person.

The investigator tells of 13-year-old Bernard, whose trouble had first shown itself in kindergarten but who, in spite of his jerking, writhing, and uncontrollable sounds, became expert in both baseball and basketball. Reports Cohen: "His movements were attributed to 'an allergic or asthmatic personality' by a pediatrician. At age 12, he appeared to be a very husky, friendly youngster, whose language comprehension and production were normal, whose intelligence was within the normal range, and who was able to form warm and meaningful social relations," even though he was teased for his jerks, grimaces, and sounds.

To treat the youngster, Cohen used slowly increasing doses of haloperidol, a drug often used in treating schizophrenia, though probably not to the same extent as chlorpromazine and other phenothiazines. These slowly increasing doses "completely eliminated all the symptoms," Cohen reports. At a certain level of medication, Bernard was able to say that he felt like making a movement or saying a word, but could inhibit it. At a higher level, he no longer felt the urge. When the medicine was reduced, several of the movements reappeared. When it was increased a little, the movements were again controlled.

In the case of this grimacing, jerking, spontaneous sound-making condition, how does haloperidol work? Apparently the same way it seems to work in schizophrenia. Against that major phobic illness, haloperidol and certain other compounds appear to act by blocking, at least to some extent, the action of the neurotransmitter known as dopamine. This action was discussed earlier in the section on autism.

Children like Bernard, Cohen suggests, may have a normal amount of dopamine (in any event, their spinal fluid contains a probably normal level of dopamine's breakdown products) but may be abnormally sensitive to it. This reasoning is based on the children's responses not only to a dopamine-blocking agent, haloperidol, but also to a stimulant drug. When a child like Bernard is given such a drug, his symptoms increase, "presumably because of increased dopamine in a system which is already oversensitive to it."

Cohen and Shaywitz have also thrown light on what may be at least one basic biological disorder in hyperkinetic or hyperactive youngsters—excitable children who have trouble concentrating. The dopamine turnover rates in the central nervous systems of such children, meaning the rates of production and use, "appear to be relatively reduced," an indication that their supply of dopamine may be lower than average. Cohen points out that such children benefit from stimulant drugs, which presumably increase the availability of dopamine, just as in his view they would be expected to do. On the other hand, children with either Tourette's syndrome or autism have elevated levels of dopamine turnover, an indication that they are producing too much of this transmitter. As expected, stimulant drugs make these children worse.

Each of the severe disturbances of early childhood—along with its subgroups—discussed here reflects in Cohen's view "a variety of interacting metabolic, genetic, and environmental forces." Basic to each may be disturbances in the brain systems whose proper functioning depends upon the correct amount and functioning of dopamine. And at least one ameliorative factor seems to be medicine that controls the output or use of that brain chemical.

Detecting and Doing Something About Developmental Difficulties

How can parents recognize when they need help?

When the child is an infant, Cohen points to a number of cautionary signs—for example:

Slow motor development: not crawling by 7 months for instance, or not walking by 16 months

Failure to form social attachments, such as smiling at a few months of age, knowing the parents as special people by 6 months, showing separation worries at 8 or 9 months

Slowness in comprehending language and in talking: for instance, not saying a single word at 1 year, not responding to his/her name or to voices, not using many words by 18 months

Unusual sensitivities and irritability

Problems in eating or in sleeping

Failure to show normal physical growth

Failure to demonstrate normal feelings of pleasure and pain
During the toddler years, indications that the parents need help are provided, for example, by the child's hyperactivity, aggressiveness, and failure to advance his language skills.
During the pre-school and early school years, some of the help-needed signals are troubles in learning, particularly in reading, unusual fears and preoccupations, problems in paying attention.

When parents notice such problems or are worried about anything else they consider abnormal, what should they do? Cohen advises: Turn to specialists for guidance. The first of these is the child's pediatrician or the family doctor. If the parents feel that the physician has not understood or seems uninterested in the problem, or if both the physician and the parents feel the need for further advice, they should seek out specialists—mainly child psychiatrists and psychologists specializing in children's development—who can perform developmental evaluations.

Just what is involved in such an evaluation? Cohen answers:

> The developmental evaluation of a young child should include thorough physical evaluation, including assessment of general health, sensory functioning (hearing, sight), and neurological status. Often, this may require laboratory tests, such as urinalysis, screening for genetic disorders, an electroencephalogram (EEG), blood tests, and other procedures, depending on the nature of the child's problems. Careful observation and developmental testing, performed by a specially trained professional, may require several visits to assess a child's developmental level and areas of particular difficulty. Repetition of such testing over the course of months may be needed to determine if there is progress or deterioration. Since children's development occurs in the context of family life, careful social evaluation of the family is generally required. A social worker, physician, or psychologist may spend a number of hours with the parents, learning about their own histories and the way in which the family's current functioning might influence the child.
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> Based on careful assessment, a diagnostic team may arrive at a specific diagnosis which can be conveyed to the parent. The major function of the diagnostic assessment is to formulate a plan of action or remediation, not to decide on a "label" for a child. There are several possible results of a diagnostic assessment: The parents may be reassured that their child's development is within the normal range or that his difficulties are transient. They may be given parental guidance about how to relate to a specific aspect of their child's personality, e.g., how to deal with his sensitivity or irritability, or how to help the child through a particularly difficult period. The child may require special psychiatric, psychological, or educational help, and the diagnostic assessment can help the parents and professionals structure a comprehensive program for a child when this is necessary.

As a child with developmental difficulties proceeds toward adolescence and beyond, Cohen reminds us, his needs must be constantly reassessed to make sure that he is receiving the appropriate type of help. A medicine or other therapeutic procedure that may have been helpful at one stage of growth may be useless at another. Contrariwise, new discoveries may have made more effective treatment available. The best hope is that well-trained professionals—most likely to be found in clinics and other institutions associated with medical schools—will work together as the child's advocate. This means working to advance his cause on all fronts—medical, rehabilitative, educational, governmental, and social.

The challenges are strong and numerous. "While remaining appropriately and judiciously optimistic about further understanding of the biology of development," Cohen notes, "we should keep in mind that the best we can offer most children with severe developmental disturbances today is good special education, thoughtful behavior modification, and humane care." He adds that "for the vast majority of children with autism in the United States today, even these basic needs are not satisfied."

In the long run, as Cohen emphasizes, the best hope for the prevention or amelioration of the major disorders of early childhood lies in research. The training of more researchers and the support—governmental and private, including individual—of more research into the basic causes and treatment of these disorders would certainly pay off. Within a year? Perhaps not. Within a decade? Very probably, particularly if the move toward more and more cooperative research (cooperative both *within* and *among* institutions) continues. Yet within recent years, government policy has been toward *less* support.

Conditions Helping Emotional Health

Asked what he would say to a parent who wanted to know what she could do to ensure the emotional health of her child, this child psychiatrist replied:

"Oh, I would say, 'Have fun with your child; have fun with your husband or wife.' The most important thing a parent can do—assuming that the child is within the range of normal health—is to enjoy what he or she is doing with their children. I would say: 'Don't worry—there are no gimmicks or gadgets that are really important, and there's no curriculum they should use with their 1- or 2- or 3-year-old child. An overzealous concern about mechanical things will detract them from something very important—the sense of pleasure in doing something gratifying and watching something grow."

Among other essentials for a child's healthy development, Cohen believes, are these:

- The parents should be sufficiently available so that the child can form a trusting relationship with them.
- The parents should respect the child's individuality as well as their own special needs and competencies.
- There should be consistency in handling. The child should not have to experience either numerous or disruptive changes but should be given enough new experience to be stimulated.
- The parents should feel comfortable in asking for guidance when they need it.

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ly with aphasic children and also with autistic children to control hyperactivity and to increase attention span. Basically, these techniques reward a child immediately for behavior desired by the teacher, therapist, or parent and ignore other behavior (or immediately punish the child for it).

For the treatment of severe language impairment, whether associated with childhood aphasia or with autism, Cohen offers several recommendations. Such impairment, he observes, requires "intensive, individualized, and often one-to-one special education in which the acquisition of verbal and basic cognitive skills is stressed. With specialized education and a minimal number of interruptions, lasting over years, some of these children may make remarkable progress. It has appeared to us that 'summer vacations' from special educational programs are to be avoided, as these often lead to loss of skills acquired only with a great deal of energy from child and teacher. Children do best with a teacher with whom they may work over the course of several years. This continuity is especially important for the most developmentally disabled children. For some of the aphasic children, in particular, the introduction of a sign language (American Language of the Deaf) has proven to be extremely valuable ....Instruction in sign language provides the child, and family, with a broader range of gestures. We have also observed changes in the behavior of several mute, autistic children once they were able to communicate in a more symbolic way with adults."

Atypical Personality Development

Cohen calls this name "a grab-bag term." He uses it to describe those children who from the very first years of life seem to have marked deviations in personality development and in the formation of warm and appropriate social relations. Another designation for this group is *early onset, nonautistic, childhood psychosis.* At every age these atypical or psychotic children seem to have some deviations in the way they relate to people, difficulties in the control of impulses, and problems in acquiring age-appropriate skills.

As the investigator notes, these are very much like the difficulties of autistic children. But the children with atypical personality development do become attached to other people. Moreover, they have discriminating attachments: They become attached to their mother, for example, but not to a stranger. Autistic children, though, will go off as readily with a stranger as with their mother.